

A Silent Triad of Need

Down Syndrome,
Aging,
& Dementia

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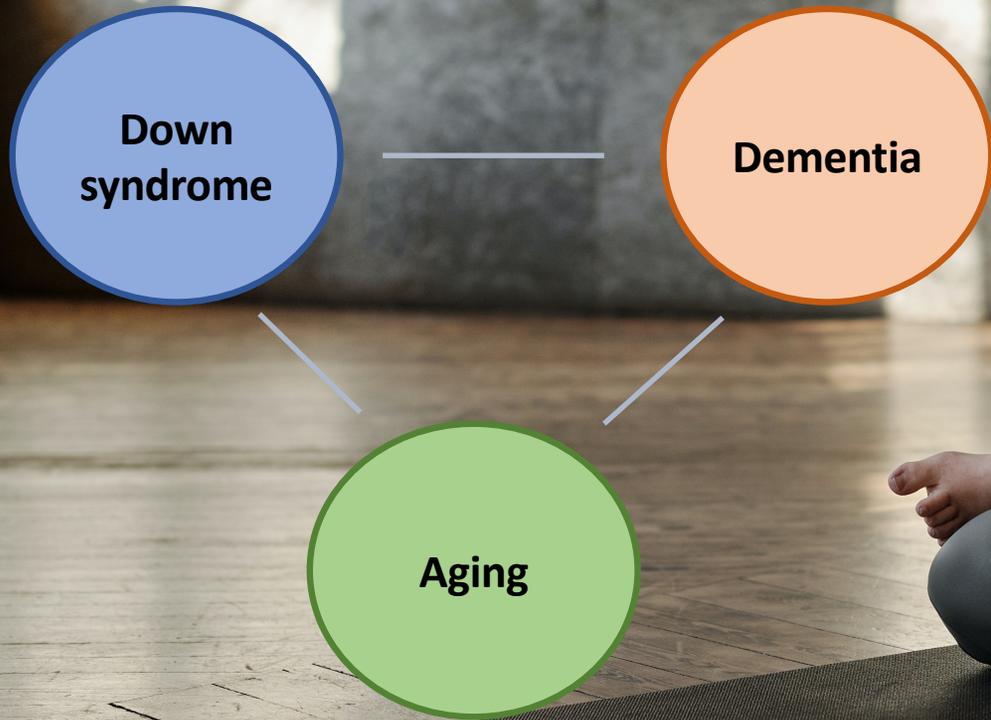
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The Silent Triad



Identifying Dementia

Common & Existing Tools

- Residential, vocational assessments, PCP
- Caregivers/family with long-term knowledge
- “Something isn’t right”

Assessments & Screenings

- NTG-EDSD
- Dementia Screening Questionnaire for Individuals with Intellectual disabilities (DSQIID)

Management Options

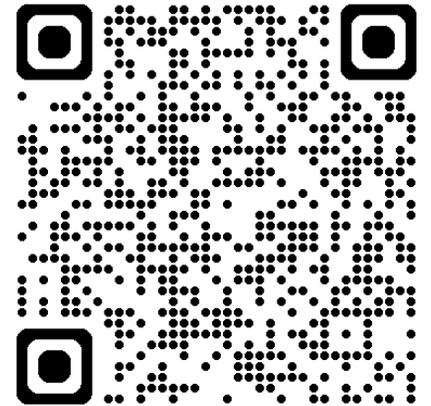
- Pharmacological (Aricept – donepezil, Namenda - memantine)
- Behavioral management
- Routine primary care
- Specialty care as indicated (Neuro, PT/OT/ST)

Other Considerations

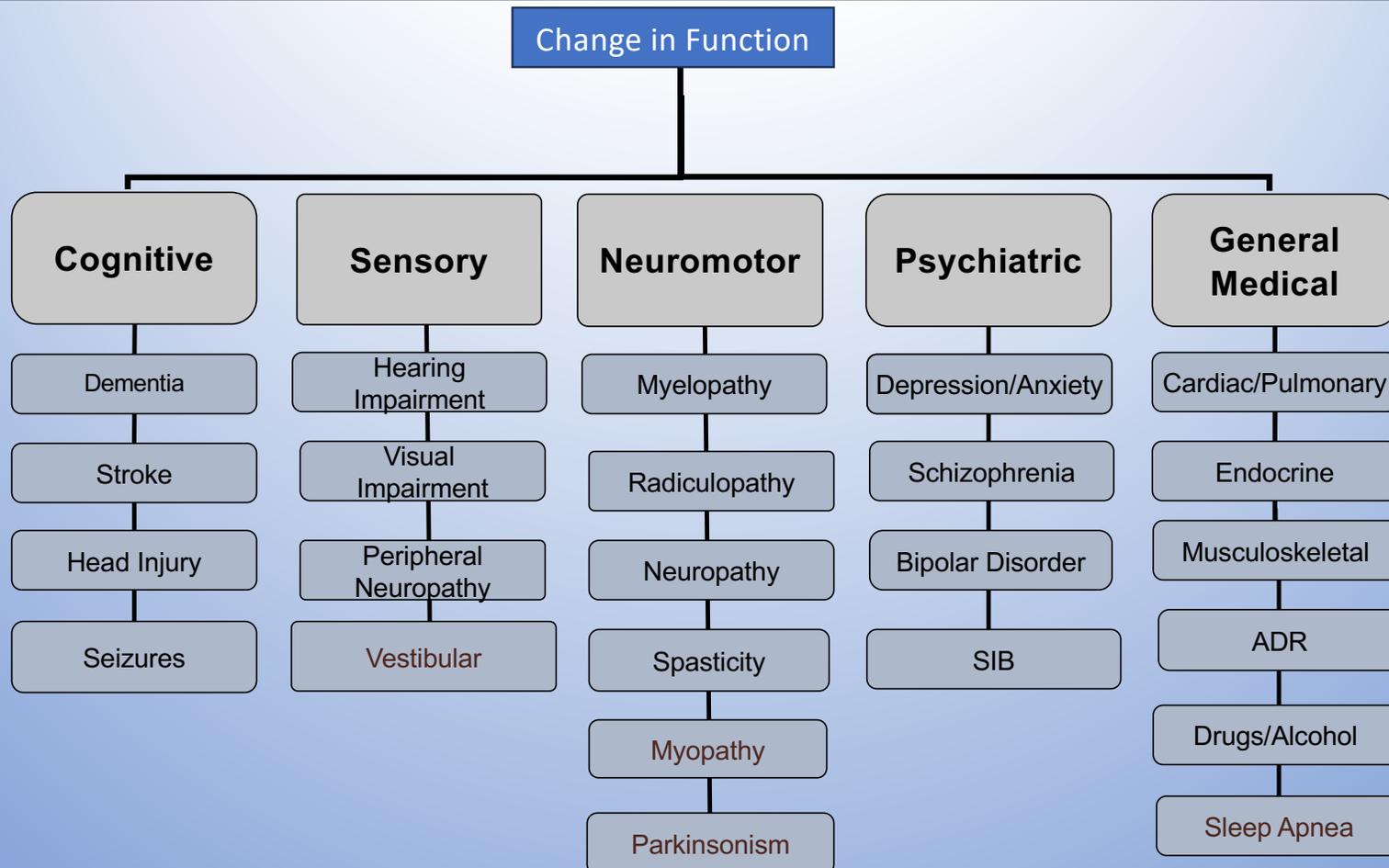
- Down Syndrome Regression Disorder (DSRD)
- “Prove to me it isn’t dementia”

Down Syndrome Regression Disorder

- Characterized by a loss of previously acquired adaptive, cognitive, and social functioning in persons with DS, usually in adolescence to early adulthood.
- Symptoms without a distinct cause
- Under the age of 40, Alzheimer's disease is highly unlikely (especially in children and young adults)
- Regression (DSDD) can be caused by one or multiple causes. Each case is unique.
- Regression, like Alzheimer's, is a "diagnosis of exclusion."



Functional decline is the decrease in physical and/or cognitive functioning and occurs when a person is unable to engage in activities of daily living



What factors can account for behavioral, cognitive, or adaptive change?

Aging with a neurodevelopmental diagnosis:
e.g., *IDD*

Aging with a mental health diagnosis:
e.g., *depression*

Medical issues – chronic, acute, comorbidities:
e.g., *arthritis, sleep apnea, high cholesterol, and hypertension*

Psychosocial stressors, past and present:
e.g., *death of caregiver (family, staff), change in housemate, move*

Meet Terry

DOB: 06.11.1959 Gender: Male Residential Name/Setting: Crescent CTH-II

Medical and Health Information

Medical Diagnoses: dysplasia of the prostate, hypertension, GERD, anemia, tinea pedis, nocturia, hyponatremia, SIADH, urinary tract infections, dementia

Medical Medications: Uroxatral, Norvasc, Tenormin, Pepcid, Ferosul Iron Supplement, Proscar, Hydrocortisone Cream, Myrbetriq, Protonix, Sodium Chloride, Detrol, Vitamin E Supplement

Psychiatric Diagnoses: Schizophrenia, mood impulsivity, acute psychosis

Psychiatric Medications: Celexa, Depakote, Haldol, Seroquel, Exelon patch, Cogentin

Intellectual Functioning: Moderate

Adaptive Functioning: Moderate

Health Concerns: hyponatremia, dementia, nocturia

NTG-Early Detection Screen for Dementia (NTG-EDSD)

- An administrative screening tool that can be completed by support staff and caregivers to note the presence of key behaviors that may be associated with dementia
- Picks up on health status, ADLs, behavior, function, memory, and self-reported problems
- Available in multiple languages
- Used to provide information to the physician or diagnostician on function and to begin the conversation leading to possible assessment/diagnosis

NTG-EDSD - page 4

	Always been the case	Always but worse	New symptom in past year	Does not apply
Memory				
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
Behavior and Affect				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
Adult's Self-reported Problems				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in "thinking"				
Changes in interests				
Changes in memory				
Notable Significant Changes Observed by Others				
In gait (e.g., stumbling, falling, unsteadiness)				
In personality (e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

NTG-EDSD

v1/2013.2

Screen for Dementia, adapted from the DSQIID[®], can be used for the early detection screening of intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff to note functional decline and health problems and record information useful for further assessment, as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness screening. This instrument complies with Action 2.8 of the US National Plan to Address Alzheimer's Disease.

that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive decline. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over a year as a family member, agency support worker, or a behavioral or health specialist using information derived by the adult's personal record).

necessary to complete the form is between 15 and 60 minutes. Some information can be drawn from the adult's health record. Consult the NTG-EDSD Manual for additional instructions (www.admd.org/ntg_screening).

Date: _____
 First _____ Last _____
 Age: _____

Instructions:
 For each question block, check the item that best applies to the individual or situation.

Current living arrangement of person:
 Lives alone
 Lives with spouse or friends
 Lives with parents or other family members
 Lives with paid caregiver
 Lives in community group home, apartment, supervised housing, etc.
 Lives in senior housing
 Lives in congregate residential setting
 Lives in long term care facility
 Lives in other: _____

NTG-Early Detection Screen for Dementia (NTG-EDSD)



NTG-EDSD

v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.8 of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

(1) File #: _____ (2) Date: _____
 Name of person: (3) First _____ (4) Last: _____
 (5) Date of birth: _____ (6) Age: _____
 (7) Sex:

Female
Male

Instructions:

For each question block, **check the item that best applies** to the individual or situation.

(8) Best description of level of intellectual disability

No discernible intellectual disability
Borderline (IQ 70-75)
Mild ID (IQ 55-69)
Moderate ID (IQ 40-54)
Severe ID (IQ 25-39)
Profound ID (IQ 24 and below)
Unknown

Current living arrangement of person:

Lives alone

Lives with spouse or friends

Lives with parents or other family members

Lives with paid caregiver

Lives in community group home, apartment, supervised housing, etc.

Lives in senior housing

Lives in congregate residential setting

Lives in long term care facility

Lives in other: _____

(9) Diagnosed condition (check all that apply)

Autism
Cerebral palsy
Down syndrome
Fragile X syndrome
Intellectual disability
Prader-Willi syndrome
Other:



ntg Resources

The National Task Group on Intellectual Disabilities
& Dementia Practices (NTG) Website

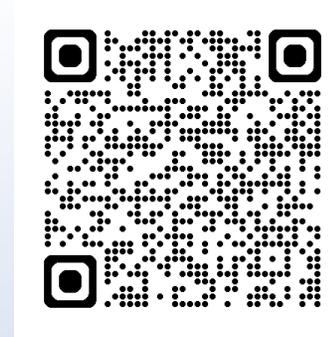
www.the-ntg.org

The NTG-Early Detection Screen for Dementia (NTG-EDSD)

<https://www.the-ntg.org/ntg-edsd>

The NTG Consensus Recommendations for the Evaluation
and Management of Dementia in Adults With Intellectual
Disabilities

[https://www.mayoclinicproceedings.org/article/S0025-6196\(13\)00371-6/pdf](https://www.mayoclinicproceedings.org/article/S0025-6196(13)00371-6/pdf)



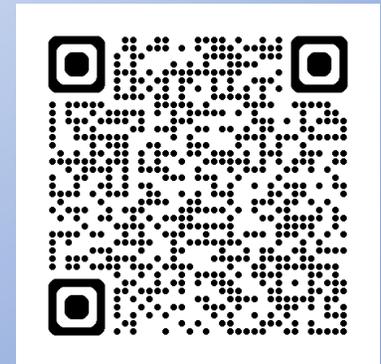
Additional Resources

NDSS Alzheimer's Disease & Down Syndrome:
A Practical Guidebook for Caregivers

<https://ndss.org/resources/alzheimers-disease-down-syndrome-practical-guidebook-caregivers>

NDSS Aging and Down Syndrome:
A Health & Well-Being Guidebook

<https://ndss.org/resources/aging-and-down-syndrome-health-well-being-guidebook>



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Questions, Comments, Discussion!

Visit  **ntg** in the
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